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'What's the Point?' - Understanding why people with Type 2 diabetes decline structured education.

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IN BRIEF

Structured diabetes education (SDE) is an evidence-based intervention that supports self-management in people with Type 2 diabetes. In the UK, healthcare providers working in primary care are responsible for referring people with Type 2 diabetes to SDE programmes. However, national audits record a high percentage of non-attenders. We explored the personal experience of living with Type 2 diabetes that led to individuals declining invitations to attend SDE programmes. The themes suggested that emotional, cognitive and social issues related to diagnosis and living with diabetes may be responsible for declining to attend SDE and that these may be masked by explanations of practical barriers. A person-centred approach to understanding the personal meaning of being diagnosed and living with Type 2 diabetes may help identify psychosocial barriers to attending SDE.

Background

Type 2 diabetes mellitus is a serious, progressive condition associated with insulin resistance and hyperglycaemia that can lead to long-term microvascular and macrovascular complications including blindness, renal failure, amputation, and premature cardiovascular disease. SDE is a key intervention that supports diabetes self-management in the UK. Healthcare providers working in primary care are mainly responsible for referring people with Type 2 diabetes to SDE. (1) A systematic review with meta-analysis demonstrated group based educational interventions improved clinical, lifestyle and psychosocial outcomes in people with Type 2 diabetes when compared with usual care. (2)

The National Diabetes Audit (England & Wales) 2016/17 demonstrated that whilst up to 90% of people with Type 2 diabetes and 50% of people with Type 1 diabetes were offered structured education, under 10% of those offered, were recorded as having attended. (3) This low attendance is thought, in part, due to inconsistent recording of this information on electronic patient records within primary care practices, with local evidence suggesting that attendance is higher at around 30%. (4) In Northern Ireland, there is no national audit, but local evidence suggests an attendance rate of around 60% (Personal Communication).

A recent systematic review examining patients' reasons for declining to attend SDE suggested a combination of those 'who could not go' for logistical, medical, and financial reasons and those 'who would not go' citing reasons related to knowledge, emotional issues, cultural issues and no perceived benefits. (5)

All studies in that review cited practical barriers for non-attendance such as: sessions were too long, venue too far away, no transport, unable to take time off work, other family responsibilities, other health issues etc. (6-17). Some of the studies stated other reasons including no perceived benefit (7,11-13); already knowledgeable (9,10,12); diabetes not serious (15); shame and stigma (7); doubts about its value (6,7, 9-17); purpose of programme unclear (7,9); that attendance was optional (15), doctor met needs (9,10,14,); lack of interest (6,11,16,17); negative about group education (9,12,17); avoidance and refusal (8); fear of being overwhelmed and not understanding (16,17).

In relation to diagnosis of Type 2 diabetes, a systematic review of emotional, cognitive and behavioural responses concluded that patients underestimate the seriousness of their diabetes, overestimate their ability to manage it and show limited engagement in the management of their disease (18).

People develop personal models of diabetes comprising of beliefs about symptoms, treatment effectiveness, consequences, and emotional responses to future complications. These are associated with and influence self-care. (19) A longitudinal study investigated the development of personal models in people with Type 2 diabetes from diagnosis and found that the communication of information and the way Type 2 diabetes is perceived at diagnosis determines the patient's view of their diabetes. Significantly, this persisted over the two years of the study. (20)

There is some literature hinting that reasons for non-attendance at SDE may relate to difficulty in adjusting psychologically to the diagnosis of Type 2 diabetes. Therefore, the aim of this study was to gain an in-depth understanding from participants themselves of what living with Type 2 diabetes meant to them and how this might relate to personal reasons for not attending SDE. Low attendance to structured diabetes education programmes remains a matter of concern and studies are still suggesting that practical reasons are the main causes. The literature speaks of difficulty in psychosocial adjustment to the diagnosis and living with Type 2 diabetes. This study investigates the possible links between the two.

Methods

Study Sample

Twenty adults with Type 2 diabetes who participated in Phase 1 of a larger study examining why adults with Type 2 diabetes decline to attend structured diabetes education and who consented to be re-contacted were purposively sampled. (21) As in the larger study, those sampled came from 2

culturally different countries within the UK; England and Northern Ireland. Demographic data collected was minimal as the intention of this study was to collect rich descriptions of participants' lived experience of Type 2 diabetes and their perceived barriers to attending SDE.

Data Collection

A Topic Guide developed by the Steering Group and informed by the results of Phase 1 of the study was used to carry out in-depth interviews either face-to-face or by telephone. (Table 1) Following training, interviews, were carried out by MS and MC, and averaged 30-90 minutes with face to face interviews being longer. Questions were open-ended to enable participant-led responses thus capturing the unique experiences for each participant's life with diabetes. Interviews were digitally recorded and transcribed verbatim. Field notes were made by the interviewers reflecting on points of interest and used in researchers' discussions.

All those who participated in the interview received a £15 voucher. One interview was excluded as it became apparent the participant had only attended 3 hours of a 6-hour programme.

Table 1 Topic Guide

Data Analysis

A realist / essentialist thematic analysis approach was used to find repeated patterns of meaning within the data.[22] Interviews were listened to and read repeatedly to acquire a deep familiarity with the data. During this process notes were made as codes emerged. An inductive approach to the analysis formulated meaningful categories and themes from the codes. [22]. A coding matrix was constructed using a framework approach to manage the findings [23]. This enabled a robust and transparent method of analysing cross-sectional descriptive data. (22). Initial categories and themes led to refined categories, final themes, and the development of core concepts.

The researchers, who were from a variety of backgrounds (clinical nursing, academic nursing, social science and biomedical science) independently analysed data and met regularly to reflect on findings, identify preconceptions and biases, and reach consensus.

Rigor

Throughout the study, authors attended to issues of trustworthiness including credibility, transferability, dependability, confirmability and reflexivity. [24]. Credibility was enhanced by data collected from 2 different countries with separate cultures within the UK (data triangulation); multiple methods of data collection including in-depth interviews and field notes [method triangulation]; researchers carried out interviews following joint training, and all researchers contributed to the analysis (investigator triangulation). Transferability is intended by the thick descriptions of the data which ensures readers have a meaningful understanding of the participants' experience and know if it is transferable to their or others' settings. Dependability and confirmability are demonstrated by using a framework approach to manage the data providing transparency of the process from coding through to the core concept. Records of the researcher meetings were also kept as an audit trail. Reflexivity was very much part of the process during researcher meetings to discuss findings especially in addressing preconceptions and bias.

Results

Demographics

Table 2 Demographics

Age range of participants was 32-79 years. Duration of diabetes was from 1 year to 28 years. Ethnicity of the participants was predominantly White, despite efforts to recruit from ethnic minorities. All participants had been invited to attend SDE within the previous 2 years. Those with a shorter

duration had been invited to SDE closer to diagnosis and those with a greater duration had been invited to SDE when they had established diabetes.

Core Concept, Themes and Categories

Six themes and 19 categories were identified. No new points were being raised by the time 20 interviews were completed and so it was considered data saturation had been attained.

Core Concept – 'What's the point?'

The core concept was '**What's the point?**' Each significant statement within each interview could be qualified with the statement 'What's the point?

The core concept and theme 'What's the Point?' can be illustrated by this quotation:

'if I just went to the doctors and they said, right here are the results actually nothing's changed, it hasn't improved it hasn't deteriorated, steady as you go, just carry on taking this medication, and by the way go and do this course, I'd say well 'what's the point', or if it's improved 'what's the point of going'? I'm on the right path.' LC1062

Figure 1 Core Concept, Themes and Categories

Theme 1 - 'What's the Point?'

This theme applied to 18 of 19 participants. Within this theme are 4 categories: '**Feel well-must be well'; 'Fatalistic attitude'; 'I'm being looked after'; 'I know enough'**.

'Feel well- must be well' illustrated the difficulty that most participants had with understanding the idea that Type 2 diabetes is a condition that could be doing silent damage in the form of vascular complications. '*I felt great, probably as good as I felt for 9, 10 months. You know, so that was probably another reason why I felt I didn't need to go.' T2143.* Most participants stated that they thought they would attend SDE if things started to go wrong and they developed complications, indicating that they had a limited concept of prevention and their own role in their diabetes management. *'Maybe if my toes started to fall off or something, something devastating like that started to happen, I think, oh my goodness maybe I do need to be educated but for me it's all, it's all positive.' T2185*

A **Fatalistic Attitude** was expressed in varying guises. For example, one person because of her religious beliefs: *'the Lord has your life laid out for you, you're born the day you die, your life is laid out in front of you, so no matter what you do, you'll go, so … I suppose I grew up with all them philosophies but still...' T2090.* An another spoke of her family history; *'it didn't bother me for the simple reason that it was in the family… Can't do anything about it. You can't turn back the clock… You know, you just forget about it.' T2002* Fatalism is defined as a belief that something is predetermined and therefore there is a powerlessness in changing that thing. Fatalism has been recognised as a barrier to self-care in people with Type 2 diabetes. (25) Someone with a fatalistic view of the diagnosis of their type 2 diabetes may not see the point of attending SDE especially if they believe personal influence is limited.

The participants that contributed to the category **'I'm being looked after'** showed an interest in being on the receiving end of diabetes care however did not recognise that diabetes care involved self-management and an active partnership between him/ herself and healthcare provider.

'I went to the nurse last week and she takes your blood pressure, goes through all the tests that have been done, the diabetes and all the rest of it and everything was fine.' LC1139

Being looked after could also relate to involvement of other members of the family. *'The last thing you want to do is go and sit down and be lectured to for 2 or 3 hours, probably being told stuff, because again, my wife being what she is, is on the internet and checking everything right through, the dos and don'ts, and they give you a lot of literature that my wife read from cover to cover'. T2143* This quotation suggests an aversion to didactic education, *'being lectured to,'* and being happy to relinquish responsibility to his wife.

'I know enough: 'Participants described receiving education at diagnosis from their primary care nurse and/or dietitian or through family members who also lived with diabetes. Others used the internet or read leaflets to obtain information. *'The nurse, when I was diagnosed, she told me everything about diabetes and gave me all the information that I needed'.* These participants felt informed which, for them, negated the need to attend education.

Theme 2 - 'What I don't know will not annoy me' – avoiding the reality.

Six participants either denied, avoided, or minimised negative feelings about having type 2 diabetes. This theme had 3 categories: '**Don't want to think about it,' 'Don't want to hear about it', 'Don't want to know about it'**. Avoidance is recognised as a coping strategy that protects the individual from the stress of an external experience, in these cases, being diagnosed and living with diabetes. Three quotations below demonstrate the breadth of avoidance behaviour expressed by participants.

'Don't want to think about it' - Avoiding thinking about diabetes.

'Now it just doesn't bother me, I never think about it…' T2010

'Don't want to hear about it' - Avoiding listening to others;

'… and I wasn't going to sit in a room and listen to possibly some people 'crying in their milk' that they'd got diabetes…'LC1128

'Don't want to know about it'- Avoiding information;

'It gets shoved to the back and what happens is you drift and drift and then something has to bring you back. Now you could argue that when my doctor said did I want to do it (attend SDE) *then that was the time to say yes, but you're sitting there at the time thinking well 'what are they going to tell me that's new? Nothing'. It's a self-denial job that is - really.' LC1084*

Attending group education for some might challenge this personal coping strategy if there is a perception that they will be exposed to the reality of their own stress or subjected to the distress of others. Avoidance coping is considered maladaptive. A recent study examining coping profile scores in people with type 2 diabetes, and including avoidance and suppression, consistently and significantly was associated with the presence and severity of depression (26)

Theme 3 - 'Make It Real'.

Eleven participants struggled with the reality of believing they have a serious condition that could be damaging in the long-term. Three categories contributed to the theme of 'Make it real': '**Doesn't feel real'; 'seeing is believing'; 'scare tactics'.** Type 2 diabetes is a condition where many people are diagnosed without symptoms and so this requires trust in the clinician to make the correct diagnosis. *'You know, pain and disability is a motivator. And the snag with Type 2 diabetes is it doesn't particularly give you any. As I say, the principal problem with it is, it's a score on a machine.'* LC1117

To make it real, some participants expressed a wish for themselves and others with Type 2 diabetes to receive threat messages. They believed being confronted with frightening facts about diabetes would make it tangible and consequently encourage attendance at SDE. They suggested that visual representation of complications, especially amputation, could achieve the necessary impact to make having Type 2 diabetes feel real*. 'I think they should give you full information to maybe scare you … they say, seeing is believing … the things you're told is a bit wishy washy … it's not hard hitting enough.'* T2057 However some participants stated that verbal threats could be perceived as persecutory. The following quotation starts off mimicking the doctor and suggests that using 'scare tactics' can be met with scepticism. *' 'Aw you know you're going to have to take them, (medication) cos if it goes on, this can happen, and that can happen…', you know, he (doctor) just throws the worst-case scenario at you. But, to me, they were all scare tactics so'.* T2010

The theme 'Make it Real' speaks first of the difficulty that people have of believing that they have the condition and secondly, that they could develop diabetes-related complications. Participants made suggestions about education being *'hard-hitting'* and using photographs or other means that might

explicitly drive home the reality of diabetes complications. The structured diabetes education programme known as DESMOND was designed to make sure that 'threat messages' defined as information about the complications of diabetes, were followed up by providing the opportunity for attendees to develop action plans that limit personal risks. (27)

Theme 4 'I feel like a number' – disease focus

The two categories in this theme are '**Feeling unsupported'** and '**I feel like a number'**. Eight participants described relationships with healthcare professionals (HCPs) that were limited in terms of support, both professionally and at a personal level. Feeling unsupported included not being acknowledged for the achievement of losing weight or quitting smoking. The participant below was angry about lack of follow-up when he had stopped taking medication;

'*Like, in six or seven months, I haven't applied for any new prescriptions for any new medication or anything and nobody's following up, nobody's checking up or nothing... Whereas if it was my previous healthcare team, they'd have been straight on the ball, 'why have you not ordered your medication?'* T2010

The phrase 'I feel like a number' reflected the sense some participants had that HCPs do not consider the individual's diabetes in the context of their lives. Many referred to the focus on test results rather on how the participant might be feeling about living with Type 2 diabetes illustrated by the quotation below:

Because the one thing I do notice when you go in there is again, it's a case of what's your scores? What's the numbers? Your blood sugar level is x, your cholesterol level is y. The one question that doesn't seem to get asked is "How do you feel?" you know "What's your actual wellbeing quotient? How do you rate your personal health?" LC111

There was a sense of hurt and underlying anger from participants who described this distant and impersonal relationship with their HCP thus illustrating the core category 'What's the point?'

Theme 5 – 'I feel valued': person-centred focus

Conversely to Theme 4, 9 participants felt very well supported by their HCPs. The 3 categories contributing to this theme were: **Ease of access; relationship continuity; feel supported and valued**.

Ease of access to their HCP is exemplified by this quote; *'It gives me a bit of confidence I suppose, anything slightly wrong and all I need to do is pick up the phone and leave a message for her and she'll ring me straight back'* LC1073.

Providing ease of access communicates a message that healthcare providers take type 2 diabetes seriously and invites patients to also take it seriously. **Relationship continuity** between patient and HCP can lead to trust and more effective partnership working as both get to know one another as individuals

'She's my nurse and you see the same girl every time which is great…'. T2185

She saw me every time … she would always have kept me right with my medication and stuff T2010

Feel supported and valued was a category that led these 9 participants to speak warmly of their healthcare provision;

'But they gave me the impression that you're important … If it (diabetes) *did change in the future… I would say, first thing I would do is ring Dr. ****'* T2143

This level of support however detracted from attending SDE because participants were invited to contact their HCPs when and if problems arose. Others would receive one to one education on routine visits. Person-centred care is what many HCPs aspire to provide and the accounts by these participants certainly valued this approach. However, participants did not see the point of attending SDE when their needs were being met directly through their healthcare provider.

Theme 6 – Practical Barriers – 'Life gets in the way'.

There were 4 categories within this theme applying to 14 participants. They are; **illness/ bereavement; too busy; work/vacation**; and the most frequent being that the **sessions were too long**. Well recognised and described elsewhere are the many practical barriers which befall everyone from time to time (6-17) These include **Illness / Bereavement** where bereavement can be illustrated by this quote *'It wasn't long after my brother had died'* T2057; and illness described in this quote *'But because I was ill, I couldn't get to the DESMOND place'.* LC1610.

There were hints by some of the participants that some practical barriers might imply a lack of prioritisation especially because there seemed to be little aspiration to seek future education classes. Some described themselves as **Too busy** *'But every time I wanted to go to learn, it was just the wrong time, and things were happening…' T2137.* Others found that work and vacation got in the way.

Work / vacation *'A bit of work came in at that time and I just went to work' T2011; '…and then I went on holiday, so I missed that and that was that then'.* LC1106. This lack of prioritization is not a judgemental attribute but emphasizes the core concept of this study 'What's the point', and the important role of the healthcare provider in helping the patient to make sense of their Type 2 diabetes and what they would gain by attending SDE. If practical barriers do prevent attendance the option to attend SDE at a future date should be supported.

Sessions too long

In addition, and noted in other studies, is the issue of sessions being too long. (20) Two 3-hour sessions may be an issue for those who have other responsibilities related to their work or home lives. The quotation below however suggests a lack of confidence about managing '3 hours of information' and that the programme is envisioned as being like school.

'But you think to yourself maybe 3 hours of information would be too much to take in at one time. You know- if they could spread it out an hour at a time- it's like going back to school again…' T2002

Within any cohort of adult learners there will be a diversity of age and educational attainment. Previous educational experience, if negative, may also contribute to resistance to attending. If a didactic delivery of education is imagined this may remind them negatively of school. The sessions may be perceived as too long but for some this may reflect internal concerns about ability to cope with new information and skills.

Discussion

Nearly all studies examining why people with Type 2 diabetes do not attend SDE cite practical and logistical reasons. However, we suggest that for most of those interviewed, practical reasons mask underlying emotional, cognitive, and social issues connected to the experiences of being diagnosed and living with diabetes. This suggests more complex barriers to attending SDE than previously acknowledged. The systematic review of emotional, cognitive, and behavioural responses to the diagnosis of diabetes, cited above, concludes that psychological adjustment to the diagnosis of Type 2 diabetes is variable and relates to symptom experience, prior knowledge, and information and treatment. (18). They also suggest that lack of overt emotional distress may be a marker of avoidance behaviour illustrated in Theme 2 'What I don't know will not annoy me'.

Lack of symptoms at diagnosis, prior knowledge and information and treatment may also be reasons why most of those interviewed had no real understanding that preventing complications requires action prior to these developing and many thought that attending SDE might be something they would do if complications were to develop. The category 'Feels well – must be well' suggests health beliefs that minimizes the seriousness of the condition and vulnerability to complications. (18)

Themes 4 and 5 describe philosophically opposing relationships with HCPs. These can both unintentionally affect attendance at SDE. Recent results of the large IntroDia® survey showed that

73% of 6753 physicians surveyed agreed that the conversation at diagnosis of Type 2 diabetes impacts the patient's acceptance of their condition and subsequent quality of patient self-care. (28) There was an undercurrent of anger and rebellion in those who felt 'like a number' because of limited engagement with HCPs. Participants expressed a sense of being told what to do in a paternalistic way possibly reminding them negatively of a teacher/ student relationship. This made attendance to SDE programs unlikely if they perceived experiencing more of the same.

One of the traps in a person-centred approach can be to inhibit the patient's problem-solving skills rather than facilitating them by equipping them, through SDE, with knowledge, skills, and confidence to self-manage effectively. (29) Participants who described experiencing a person-centred approach from their HCPs still require a clear message about the importance of attending SDE.

Theme 6 addressed some of the practical barriers to attending SDE such as work, holidays, illness etc. - well documented elsewhere (6-17). The issue of perceived lengthy SDE sessions has been observed in other studies. (20) This may require consideration for those who have practical challenges arising from other responsibilities however it was clear that many participants declined SDE because they perceived a didactic delivery of education reminding them negatively of school experiences.

Throughout all the narratives from the participants in this study was the possibility of lack of sufficient explanation, description and justification on the part of the referring clinician about what the participant would gain from attending a SDE programme. This has been highlighted in a recent study which calls for more effective clinician promotion of SDE. (30)

Strengths and Limitations

A strength of this qualitative study is that it gave voice to people with Type 2 diabetes who declined SDE and are traditionally considered hard to engage. The participants from 2 countries in the UK with different cultures, expressed similar concerns despite divergent life experiences. The themes were spread more or less equally across the participants from both countries.

3 limitations of this study are addressed. First, we were not able to identify emotional issues that prevented engagement with SDE however an underlying anxiety, fear, or shame is suggested. One recent qualitative study elicited the experience of shame and stigma in some people with Type 2 diabetes who chose not to attend SDE. This manifested as not wishing to let anyone know about their diagnosis. (7) Another study describes avoidance and refusal which included diabetes being a low priority, unwillingness to change behaviours and not wanting to meet others with Type 2 diabetes. (8).

Second, despite best efforts to engage mixed ethnicity, only one participant was of Pakistani origin. Subsequent research needs to address the engagement of a more diverse population in this already hard to reach group of people with Type 2 diabetes.

Third, we did not systematically collect exhaustive demographic information such as HbA1c, comorbidities or diabetes complications. This information would undoubtably add an extra dimension however a strength of this study is that the qualitative investigation enabled individuals to express freely, their thoughts and feelings about living with diabetes and how it relates to not attending SDE. Some of this demographic data may have risen naturally during interviews as part of the lived experience.

Future Research

Further research needs to identify more specifically, the underlying emotional aspects of being diagnosed and living with diabetes, such as shame, anxiety and feeling stigmatised and how that relates to declining SDE. This should be linked to how healthcare providers can best explain type 2 diabetes, diabetes complications and the patient's role in self-management. What sense people make of those explanations, especially at the first consultation, also needs to be evaluated.

Conclusion

Supporting people with Type 2 diabetes to attend SDE requires a collaborative, person-centred dialogue, between referring healthcare providers and the patient. This approach can address underlying emotional, cognitive, and social issues related to living with diabetes, preferably around the time of diagnosis, to influence positively, the patient's personal model of diabetes. This should include discussion of the seriousness of Type 2 diabetes and some of the personal barriers such as diabetes not feeling real. This in turn can lead to more successful promotion of structured education programmes. This approach may have implications for professional training.

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Duality of Interest

Florence Findlay-White was employed part-time by Diabetes UK in a healthcare professional role. This research was carried out as an independent researcher in her own time. No further potential conflicts of interest related to this article are reported

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Author Contributions

FFW, MMS, MEC & VEC Researched the data, **FFW & VEC** wrote the manuscript **FFW, MMS, MEC & VEC** contributed to discussion, reviewed and edited the manuscript. **FFW** is the guarantor of this work and, as such, had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the analysis.

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